# STANDARDS FOR CONFIDENTIALITY, DISCLOSURE OF DATA, AND QUALITY ASSURANCE

## **Confidentiality**

Data obtained under the Texas Cancer Incidence Reporting Act are for the confidential use of the Texas Department of Health and the persons, public or private entities that the Board of Health determines are necessary to carry out the interest of the Act. The data are privileged and may not be divulged or made public in a manner that discloses the identity of the patient. All reporting entities that comply with the Act are immune from liability for furnishing the required information.

#### **Disclosure of Data**

All data reported to the TCR are available for use in aggregate form for analysis by registry staff, cancer researchers and the public. Reports of the incidence of cancer for the state can be generated. Public access to aggregate data is available through published reports or through the TCR, if in accordance with its data release policies and procedures.

The TCR may exchange patient-specific data with the reporting facility, any other cancer-control agency, or clinical facility for the purpose of obtaining information necessary to complete an abstract or follow-up information, provided these agencies and facilities comply with the TCR's confidentiality policies. However, no hospital-specific patient information can be released unless authorized under law. The TCR can contact the facility where the patient was seen and obtain consent to release information other than that authorized by law.

To achieve complete case ascertainment, the TCR **may** exchange patient-specific data with other state cancer registries if reciprocal data sharing agreements and confidentiality provisions are implemented.

The TCR may grant researchers access to confidential information concerning individual cancer patients, provided those researchers comply with the provisions and confidentiality policies mandated by the Texas Department of Health's Committee on Requests for Personal Data.

### **Quality Assurance**

The TCR has an elaborate series of quality assurance procedures that were developed based on the SEER Program, CDC recommendations and NAACCR standards. These procedures, which consist of both internal and external processes, insure the reliability, completeness, consistency and comparability of TCR data.

The internal process includes a review of each hard copy abstract for multiple primaries, duplicate records, and valid codes for each field. As data are uploaded into the system, it is intensely scrutinized for identification of:

- possible duplicate submission of existing records
- unacceptable codes for any field or interfield inconsistencies and
- invalid or unusual site/sex, age/site, age/morphology or site/morphology combinations.

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# Standards for Confidentiality, Disclosure of Data, and Quality Assurance, continued

The TCR is currently working on data upload procedures which will check submitted records for errors. Any submission in which there are more than an acceptable percent of errors will be returned to the institution for correction and re-submission. If records are returned to your facility for correction, they will not count towards your compliance.

The external process includes:

- hospital training
- casefinding studies
- reabstracting studies and
- death clearance

**Hospital training** includes the continuing education and training of cancer registrars as well as medical records personnel on standards and procedures for reporting. Requests for training and technical assistance should be directed to your appropriate regional program.

Casefinding includes the TCR's review of casefinding sources such as hospital disease indices, pathology reports (including cytology and autopsy reports), outpatient records and appropriate oncology logs for missing cases. Sometimes a chart review may be performed on records identified from the audit to determine reportability. For recommended casefinding procedures please see Appendix M.

**Reabstracting studies** involve the complete reabstracting of a sample of reported cases without reference to the original abstract. Discrepancies are identified and used to assess the quality of the hospital's cancer case reporting and training needs.

**Death clearance** is an additional check of reporting completeness. Each year the data management section of the TCR will match existing incidence cases against the BVS death certificates. If a match is found, the date of death will be updated for that record in the TCR database. Hospitals will be queried on cases in which a report was not received and an abstract must be submitted for all missed cases. In some instances, there may not be evidence of active cancer. If there is no documented evidence of a reportable diagnosis, please query back to your regional program manager to determine if this case is indeed a death certificate only case.

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